

RDI Youth Leadership Programme

These Terms of Reference outline the structure and functioning of the Youth Leadership Programme, developed by Rare Diseases International (RDI). The Programme is designed to engage and empower young people within the rare disease community, ensuring their perspectives are represented in global discussions and decision-making processes. It provides a platform for young leaders to contribute their insights and expertise while fostering capacity-building and collaboration across the rare disease ecosystem.

1. About RDI

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities. RDI has more than 100 member organizations from 48 countries, that in turn represent rare disease patient groups in more than 150 countries worldwide. Throughout a lifetime, Persons Living with a Rare Disease (PLWRD) and their families face multiple forms of social discrimination, as well as common challenges in accessing diagnosis and care. As an alliance, RDI works to ensure greater equity for all PLWRD and their loved ones across the globe.

2. Programme objectives

The RDI Youth Leadership Programme aims to engage young talent to ensure RDI aligns with the needs and expectations of the next generation.

The Programme is designed to provide mentorship and capacity-building opportunities to help young leaders develop the skills needed for impactful initiatives. It also focuses on facilitating engagement in key forums and events while supporting participants in building networks within the rare disease community.

Additionally, the Youth Leadership Programme will contribute insights and guidance to inform RDI's strategies and actions. By incorporating fresh perspectives, it seeks to bring innovative ideas that are essential for staying relevant in a rapidly evolving world.

3. Target Audience

Applicants to the RDI Youth Leadership Programme must be between 18 and 30 years old and demonstrate basic proficiency in English, as the Programme's activities and discussions will be conducted in English. RDI Membership is not a firm requirement for eligibility, but priority will be given to RDI Members. The Programme aims to ensure a balanced representation of geographic diversity, gender, and diverse backgrounds among participants. Applicants should either have lived experience with rare diseases, whether as a person living with a rare disease (PLWRD) or as a relative of a PLWRD or possess relevant experience in the field of rare diseases as an advocate.

4. Application & Selection Process

The selection process will ensure transparency and equal opportunities. It will begin with a call for interest, where an email invitation to apply will be sent to RDI members by the end of December 2024.

Applications will be open for submission from the time the email is sent **until the 31st of January 2025**. Once all submissions are received, applications will be reviewed by the RDI Team, and shortlisted candidates may be invited for an interview to assess their motivation and suitability for the Programme.

Applicants should follow these steps to apply:

1. Complete the application form: <https://forms.office.com/e/MCXLRJMSn>
2. Create a video presentation (maximum 90 seconds) introducing yourself, your experience, and your motivation for joining the Programme.
3. Submit all materials through the application form

The primary selection criteria will include:

- **Motivation:** passion for rare disease advocacy and clear leadership growth goals.
- **Experience:** proven leadership and contributions to advocacy or community initiatives, ideally through an RDI Member organization, but other relevant experiences would also be valued.
- **Lived Experience:** personal connection as a PLWRD, family member or caregiver.
- **Diversity:** representation across regions, socio-economic backgrounds, and genders.

Candidates will be notified of the final selection by the end of February 2025. The selected candidates will be publicly announced on Rare Disease Day 2025.

Selected candidates will be asked to sign the Terms of Reference to formalize their understanding of and commitment to their roles and responsibilities within the Programme.

5. Commitment & expectations

Participation is voluntary and lasts for the duration of 2 years, renewable up to 3 times.

Members are expected to commit time to attend quarterly virtual meetings on Microsoft Teams, actively engage in Programme activities, collaborate with one another, and represent the voice of youth at a national, regional and global level.

There will be four online meetings per year, in addition to one in-person meeting annually. Please see section 9 for the dates of the first two virtual meetings and the in-person event.

6. Programme overview

6.1 Programme's Pillars

The aim of the **RDI Youth Leadership Programme** is to elevate the role of youth in shaping the rare disease agenda at global, regional, national, and local levels, while supporting RDI in aligning its strategies with the next generation's needs. To achieve this, the Programme will center its efforts around three key Pillars:

- **Leadership & Empowerment:** enhancing leadership capabilities among youth in the rare disease community through structured mentoring, training, and practical experience. The goal

is to equip young leaders with the skills, confidence, and tools needed to assume leadership and advocacy roles, empowering them to drive impactful initiatives and meaningful change in the rare disease community;

- **Collaboration & Networking:** strengthening connections among youth leaders, RDI members, external organizations, researchers, and key stakeholders to foster meaningful collaboration. By promoting collaborations that amplify youth voices and impact, the objective is to build a robust ecosystem for advancing the rare diseases agenda through knowledge sharing, joint initiatives, and networking;
- **Advocacy & Visibility:** empowering youth leaders to become influential advocates for rare diseases by highlighting the challenges faced by PLWRD and championing their recognition as a global health priority. The goal is to elevate the visibility of rare diseases at local, national, and global levels while equipping youth leaders with the tools and strategies needed to drive impactful advocacy efforts.

6.2 Timeline & activities

In Q1 and Q2 2025, the Programme will concentrate on understanding and discussing the World Health Assembly (WHA) Resolution on Rare Diseases. This focus will prepare the youth leaders for meaningful participation at the in-person event scheduled for May 2025. These early sessions aim to equip participants with a deep understanding of the resolution's implications and how it shapes the landscape of rare diseases globally.

Following the event in May 2025, the Programme's content will focus on more dynamically reflecting the specific needs and interests of its members. This adaptive phase will allow for a more participant-driven approach, where the topics and activities will be directly shaped by the feedback and expressed interests of the youth leaders. This could include more specialized workshops, or further training, depending on what the participants identify as most valuable for their development and impact in the rare disease community. This flexible structure ensures that the Programme remains relevant and engaging, fostering a proactive and empowered group of young leaders in the rare disease field.

7. Governance and Structure

The Youth Leadership Programme is composed of a Secretariat, two Co-Chairs and the 10-15 Programme members. The governance and structure of the RDI Youth Leadership Programme is designed to facilitate the coordination of activities, and ensure alignment with the RDI's vision, mission and objectives. The Youth Leadership Programme does not function as a decision-making body, nor does it have authority over the independent work and activities of its members outside the scope of the Programme.

7.1 The Secretariat

The RDI Secretariat will oversee the activities of the Youth Leadership Programme and will provide administrative, logistical, and organizational support to ensure the smooth functioning of the Youth Leadership Programme.

More specifically, key responsibilities of the Secretariat are as follows:

- Serves as the primary administrative and operational support, coordinating all logistical aspects of the RDI Youth Leadership Programme, including meeting organization and preparation of materials;

- Facilitates communication between the Youth Leadership Programme members, the RDI team, the RDI Council, and external stakeholders, while managing communication platforms and materials to foster collaboration and promote the programme's initiatives;
- Coordinates participation of Youth Leadership Programme members in RDI meetings, or other events including workshops, in-person meetings, and campaigns providing technical and logistical support;
- Oversees the implementation of the programme's objectives and monitoring, and ensures alignment with RDI's strategic priorities;

7.2 The Co-Chairs

The Co-Chairs of the RDI Youth Leadership Programme will help in guiding the Programme's activities. The Co-Chairs will act as the main point of contact between the Youth Leadership Programme and RDI's broader governance structures.

7.2.1 Appointment

Members of the Youth Leadership Programme can nominate themselves or others for the Co-Chair role. The RDI Secretariat will review nominations. Co-Chairs will serve a term of 2 years, aligned with the overall limit of the Programme membership.

7.2.2 Responsibility

Key responsibilities of the Co-Chairs are as follows:

- Represent the collective perspective of the Youth Leadership Programme in communications with the Secretariat;
- Foster collaboration among Programme members to develop and implement creative, youth-driven projects;
- Foster an inclusive and supportive environment;
- Encourage active participation, ensuring all members feel heard and valued;
- Collaborate with the Secretariat to monitor progress of the Programme's activities.

8. Tools

RDI will provide the Youth Leadership Programme members with a range of tools and resources to ensure that they are well-equipped to succeed in their roles and contribute effectively to the objectives of the Programme. RDI will provide guidance and advice in procuring any additional tools deemed necessary by the members.

8.1 Online collaboration tools

- A dedicated platform (Microsoft Teams; WhatsApp group chat) for communication and collaboration;
- A shared drive for storing documents, resources, and presentations, ensuring that all members have easy access to materials and can collaborate in real time;

9. Meetings

Members of the Youth Leadership Programme will participate in four virtual meetings per year and one in-person meeting.

- The virtual kick-off meeting is scheduled for **March 12th** (TBC)
- The second virtual meeting will take place on **April 9th** (TBC)
- The in-person meeting will be held in Geneva, Switzerland, from **Monday, May 19th to Friday, May 22nd**.

Annual in-person meeting

The first in-person meeting will be held in Geneva during the World Health Assembly (WHA) in May 2025. Travel costs for members of the Youth Leadership Programme will be covered by RDI. A detailed agenda outlining the schedule and activities will be communicated closer to the event.

Signed Agreement

Full Name _____

Signature _____

Date _____